

STATEMENT OF THE NEPHCURE FOUNDATION
ON THE
FISCAL YEAR 2005 APPROPRIATIONS FOR THE
NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES
BEFORE THE
HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH & HUMAN
SERVICES, EDUCATION AND RELATED AGENCIES
PRESENTED BY
ED HEARN, FORMER MAJOR LEAGUE CATCHER FOR THE NEW YORK METS
AND THE KANSAS CITY ROYALS

THE NEPHCURE FOUNDATION

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April 20, 2004, 10:00 AM

SUMMARY OF RECOMMENDATIONS FOR FY05:

1. A 10% INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH AND THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK).
2. CONTINUE TO EXPAND THE NIDDK NEPHROTIC SYNDROME (NS)/FOCAL SEGMENTAL GLOMERULOSCLEROSIS (FSGS) RESEARCH PORTFOLIO BY AGGRESSIVELY SUPPORTING GRANT PROPOSALS IN THIS AREA AND ENCOURAGING THE NATIONAL CENTER FOR MINORITY HEALTH AND HEALTH DISPARITIES (NCMHD) TO INITIATE STUDIES INTO THE INCIDENCE/CAUSE OF NS/FSGS IN THE AFRICAN-AMERICAN POPULATION.
3. THE NEPHCURE FOUNDATION ENTHUSIASTICALLY SUPPORTS THE SCIENTIFIC CONFERENCE/WORKSHOP BEING SPONSORED BY THE NATIONAL INSTITUTE OF DIABETES & DIGESTIVE & KIDNEY DISEASES (NIDDK). THE WORKSHOP WILL TAKE PLACE EARLY IN 2005 AND WILL EXAMINE AREAS OF PROMISE SURROUNDING GLOMERULAR DISEASE AND WILL DEVELOP A FUTURE AGENDA FOR FOCAL SEGMENTAL GLOMERULOSCLEROSIS (FSGS) RESEARCH.
4. THE NEPHCURE FOUNDATION ENCOURAGES FOLLOW UP TO THE 2005 SCIENTIFIC WORKSHOP IN HOPES THAT IT WILL INITIATE GRANT PROPOSALS FOCUSED ON ACHIEVING THE GOALS AND OPPORTUNITIES DEVELOPED BY THE WORKSHOP.

Mr. Chairman, and members of the subcommittee, I am pleased to present testimony on behalf of the NephCure Foundation (NCF), a non-profit organization driven by a blue-ribbon panel of respected medical experts and a dedicated band of patients and families working for a common goal – to save kidneys and lives.

I am Ed Hearn, former Major League catcher for the 1986 World Series Champion New York Mets and the Kansas City Royals. My career as a professional athlete came to an abrupt end in 1991, when I was diagnosed with Focal Segmental Glomerulosclerosis (FSGS), a debilitating and degenerative kidney disease. Today, after three kidney transplants, the aid of a breathing machine at night, a \$3,000 IV once a month, and \$40,000 of medication to pay for up to 50 pills that I must swallow each day, I live to tell my story and to speak for those suffering from FSGS.

Treatment Trials Beginning, But No Cure in Sight

Mr. Chairman, FSGS is one of a cluster of glomerular diseases that attack the one million tiny filtering units contained in each human kidney. These filters are called nephrons and these diseases attack the portion of the nephron called the glomerulus, scarring and often destroying the irreplaceable filters. Scientists do not know why glomerular injury occurs and they are not sure how to stop its inevitable destruction of the kidney.

When I was a teenager, doctors found protein in my urine and told me that some day I might have kidney trouble. I pushed it out of my mind, thinking that some day meant when I was an old man down the road. Some day came faster than anyone expected. I believe that because I was a highly conditioned athlete, and catchers are more conditioned than most athletes, my body initially masked the symptoms of FSGS.

My first kidney transplant lasted more than seven years until the FSGS returned, as it often does. I received a second kidney from my aunt in 2000, but my body rejected it almost immediately, and I received a third kidney transplant in May of 2002. My story is not unique; there are thousands of other people in this country who have had their lives disrupted due to the sudden onset of FSGS. Although kidney transplants have been very successful for thousands of FSGS patients, there are many patients of whom the body rejects the transplanted kidney or the FSGS comes back and attacks the transplanted kidney, leaving the patient with no functioning kidneys. He or she must then rely on daily dialysis as a means of survival.

We are extremely thankful that an NIDDK-funded clinical trial began this year to study the efficacy of the current treatments for FSGS, and that ancillary studies are underway to examine tissue samples of injured glomerulus. However, these clinical trials hold no particular hope for patients who suffer from FSGS.

There are thousands of young people who are in a race against time, hoping for a treatment that will save their lives. The NephCure Foundation today raises its voice to speak for them all, asking you to take specific actions that will aid our quest to find the cause and the cure of NS/FSGS.

First and foremost, we support a 10% increase for the National Institutes of Health and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

When glomerular disease strikes, the resulting Nephrotic Syndrome causes loss of protein in the urine and symptoms such as edema, a swelling that often appears first in the face. For example, many physicians mistake children's puffy eyelids as an allergy symptom. Stories of similar misdiagnoses are common at our Foundation. With experts projecting a substantial increase in Nephrotic Syndrome in the coming years, there is a clear need to educate pediatricians and family physicians about glomerular disease and its symptoms.

Glomerular Disease Strikes Minority Populations

Nephrologists tell us that glomerular diseases such as FSGS affect a disproportionate number of African-Americans and, according to NIDDK, "the worst prognosis is observed in African-American children." NephCure officials have described this situation in a meeting with Dr. John Ruffin, director of the National Center for Minority Health and Health Disparities (NCMHD).

As the NCMHD becomes fully operational and plans programs, our Foundation will continue to work with the Center to encourage the creation of programs to study the high incidence of glomerular disease within the African-American population.

We ask the Committee to join with us in expanding the NS/FSGS research portfolio by requesting that the National Center for Minority Health and Health Disparities seize the opportunity to establish research into the phenomenon of glomerular disease within the African American community.

We enthusiastically support NIDDK in sponsoring a scientific workshop/conference to take place early in 2005, with the intent to review the most promising existing science in glomerular disease, and focus on methods of translating this scientific information into improved patient care. This goal is consistent with the NIH Roadmap to Research initiative developed by NIH Director, Dr. Elias Zerhouni.

The NephCure Foundation encourages follow up to the scientific workshop/conference in hopes that it will generate grant proposals focused on achieving the research goals and opportunities developed by the workshop.

Mr. Chairman, as you know, patient support and advocacy groups such as the NephCure Foundation work closely with medical research organizations. They share a mutual understanding that unless major research efforts are undertaken, advances and improvements in the health of patients will not occur. Every year, the NephCure Foundation participates in advocating increased funding for the NIH and NIDDK. We want to reiterate how deeply grateful we are for your leadership and that of the subcommittee on medical research matters, which means so much for the health of the people in our nation.

I will be pleased to answer any questions you may have.

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AA Indian River Community College, 3.75 GPA

OCCUPATIONAL HISTORY:	1978-1982	Philadelphia Phillies Baseball Club
	1983-1986	New York Mets Baseball Club
	1987-1989	Kansas City Royals Baseball Club
	1990	Cleveland Indians Baseball Club
	1991-2001	New York Life Insurance Company
	1994-Present	Professional Keynote Inspirational Speaker

**HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES
Witness Disclosure Requirement - "Truth in Testimony"
required by House Rule XI, Clause 2(g)**

Your Name:

Ed Hearn

1) Other than yourself, please list what entity or entities you are representing:

NephCure Foundation

2) Are you testifying on behalf of a Federal, State, or Local Government entity?

No

3) Are you testifying on behalf of an entity other than a Government entity?

Yes, NephCure Foundation

4) Please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 1999:

None

5) If you answered "Yes" to question number 3, please list any federal grants or contracts (including subgrants or subcontracts) which were received by entities listed under question number 1 since October 1, 1999, which exceed 10% of the entities revenue in the year received, including the source and amount of each grant or contract to be listed.

None

6) If you answered "Yes" to question number 3, do any of the entities disclosed in question number 1 have parent organizations, subsidiaries, or partnerships whom you are not representing?

No

7) If you answered "Yes" to question number 3, please list any offices or elected positions held or briefly describe your representational capacity with the entities disclosed in question number 1: *None*

Signature: Ed Hearn

Date: April 20, 2004